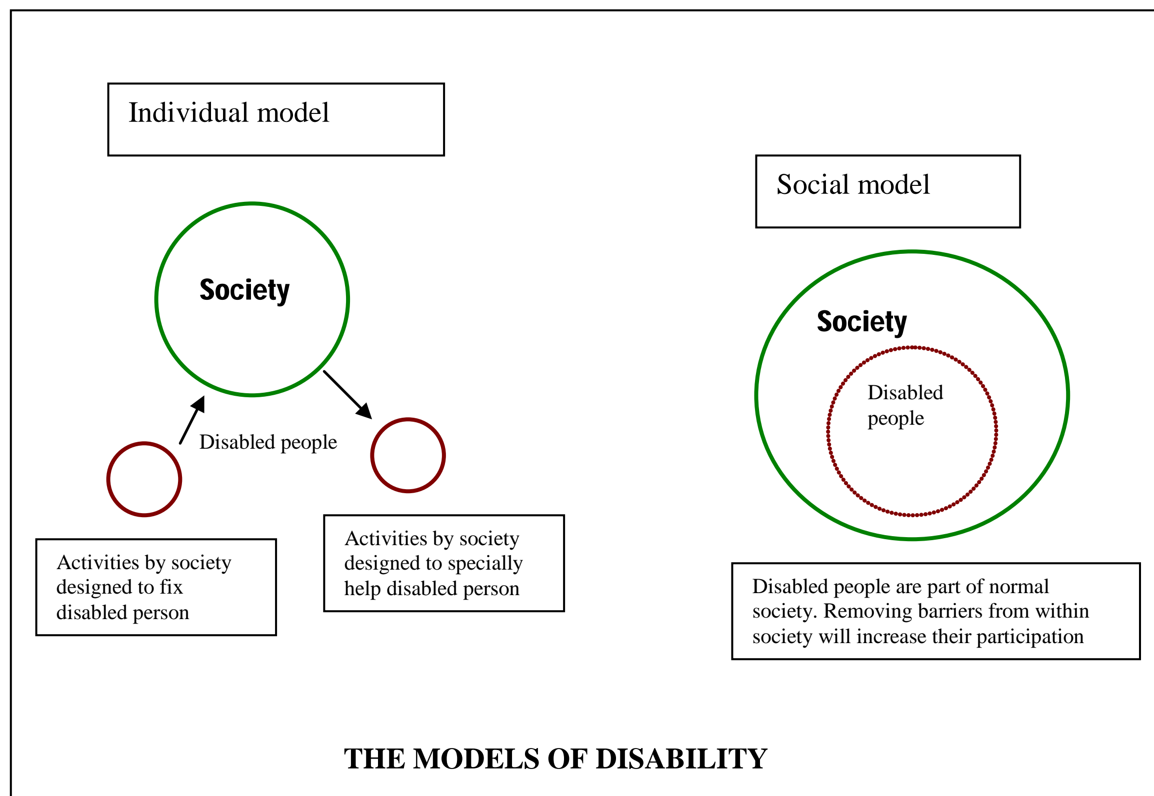
Mainstreaming disability into the MDG targets

At least one in five of the world's poorest people are disabled but there is as yet no widespread acceptance or push to ensure that 20% of the poorest recipients of aid programmes are disabled. Disabled people are so severely excluded from all areas of society that there is very little information or comparative data on the effects of disability on individual, family and community well being and almost no assessment of the economic implications of disability. But there is a very strong link between disability and poverty which implies that there is not one of the internationally agreed Millennium Development Goal targets that can actually be met without now considering how to include disabled people.

But inclusion, or mainstreaming of disability into development programming is proving to be an enormous challenge. This paper sets out to highlight some of the main reasons why this may be the case and offer some recommendations for how to overcome them.

Recommendation 1 The social model of disability needs to be adopted and promoted by governments wanting to work towards including disabled people in development targets. Training and awareness-raising on how the social model works in practice is recommended.

The first major barrier to successful inclusion of disabled people is attitude – there is a long history in development of treating disabled people as medical or charity cases with little realisation that in fact they are key community members with needs and aspirations that are the same as those around them. The following diagram highlights how the medical / charity approach has hindered progress on effectively targeting disabled people:



THE MODELS OF DISABILITY

The **individual model** of disability is the most widespread approach used in development programmes currently. The focus is always on the individual with the impairment with specialist

programmes (e.g. medical, rehabilitation or social protection based) being created specifically for disabled people.

The **social model** of disability is a new and potentially far more effective way of meeting the needs of disabled people in development. The focus is on how society creates barriers that exclude disabled people from fully participating. The negative attitudes of parents, teachers and non-disabled children for example are often the reason behind many disabled children being absent from local schools rather than their specific impairment.

<u>Individual model programming</u>
A **medical approach** focuses on the impairment the individual person has and sees it as an obstacle preventing them from fully participating in society. The focus is to “cure” or “improve” individuals with impairments in order to include or “fit” them into society. In development terms this has tended to increase the segregation of disabled people from the mainstream by focusing all efforts on the provision of specialist services. Interventions are of a medical / rehabilitation nature, carried out by specialists and are often located only in major urban areas

In the **charity approach** the disabled person becomes defined <u>*only*</u> as a passive recipient of long-term aid, gifts and other help, and not as a citizen who could be a productive member of society. In development terms this view is manifest in the tendency for aid to be delivered to disabled people via specialist organizations and for mainstream development to assume their programmes are of little benefit to disabled people. Examples might include special income generating projects or vocational training centers created specifically for disabled people rather than looking at how mainstream projects can incorporate disabled entrepreneurs. The underlying assumptions are that disabled people are not capable of working and therefore need to be supported.

<u>Social model programming</u>
The **social model** identifies three major barriers that prevent people who have impairments effectively participating in society: **attitudinal** (negative views of disabled people by non-disabled people), **environmental** (physical, access to buildings, communication issues), and **institutional** (systematic exclusion or neglect in social, legal, educational, religious, and political institutions). Removing these barriers is possible and has a hugely beneficial impact, both on the lives of disabled people and on the whole community.

Adopting the social model of disability does not mean rejecting medical services, rehabilitation, or assistance from others; but it does change the way in which services and assistance are given, placing them in the wider context of disabled people’s lives. Disabled people’s needs are basically the same as non-disabled people’s: for life, love, education, employment, full participation in society, access to adequate services (including medical and rehabilitation services when necessary) as of right, and some choice and degree of control in their lives.

In development terms this means programmes need to understand how their current practices exclude disabled people. It means taking responsibility for understanding how to include disabled people as stakeholders and beneficiaries in all mainstream work and in looking for ways to support their participation in community life.

Recommendation 2 Create policy commitments on disability inclusion
With regards to disability there is widespread lack of policy commitments – unlike gender (or more specifically women), HIV or children / youth high level public statements on the need to include disabled people by development agencies are rare. Poverty Reduction Strategies, MDG targets or ‘Education for All’ initiatives do not routinely identify the need for disability inclusion. Without this

overarching framework agencies charged with delivering aid are not put under any pressure to identify what barriers exist for disabled people in accessing their services so the issue gets sidelined and left to specialist organisations.

Recommendation 3 Collect disaggregated data on the economic and social situation of disabled people

Currently there is little accountability from mainstream programmes on how accessible their activities are for disabled people. That is because there are very few high level policy statements, commitments or targets for mainstreaming. Without the need to measure accessibility therefore we also struggle to find effective monitoring instruments – there is no disaggregated data on disability for example routinely being collected by mainstream programmes. Therefore we cannot know for sure just how many disabled people are benefitting from aid and if this aid is appropriate or not. This lack of accountability means agencies can continue to work in ways that actively exclude people and where work on inclusion is happening there is no consistency in approach.

Recommendation 4 Budget for access

Since projects do not routinely budget for access (i.e. cost of personal assistants, Sign Language interpreters, advocates, additional travel, Braille/large print translations) when these requests come up there is no obvious budget line to cover them so any expenditure has to be found from somewhere else – giving the impression this is an expensive additional cost. However put the costs into the original project concept and they will be regarded as development costs. Currently there is no systematic budgeting for access needs and yet with very little actual expenditure it could transform the opportunity for many disabled people to participate and benefit from mainstream programmes.

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APPENDIX 1

SUMMARY OF MDGs IN RELATION TO DISABILITY:

Goal 1: Eradicate extreme poverty and hunger

• Of the estimated 600 million disabled persons worldwide, 70% live in developing countries, and according to UN statistics, 82% live below the poverty line[i]. The World Bank estimates that disabled persons comprise about 20% of the poorest of the poor[ii].

• Impairment impacts not only the individual, but also their families and communities, e.g. child carers of disabled family members are often themselves not able to attend school. The lives of an estimated 25% of the population in the Asia-Pacific region are believed to be affected by disability[iii] - this represents a significant reduction in the potential productive human capital.

• As many as 50% of impairments are preventable and directly linked to poverty[iv].

• Hunger and malnutrition, and disability and poverty are intertwined; malnutrition causes about 20% of impairments[v].

Goal 2: Achieve universal primary education

• United Nations studies show that only 1-2% of disabled children in developing countries receive formal education[vi].

• United Nations Centre for Human Rights estimates that only 2% of disabled persons have access to rehabilitation and appropriate basic services[vii] (access to these services is essential to enable disabled children to attend school).

The Dakar Framework for Action – Education for All[viii], and the Salamanca Framework for Action on Special Needs Education[ix] provide guidance on actions to achieve this target with respect to disabled children.

Goal 3: Promote gender equality and empower women

• Disabled women are often doubly disadvantaged, through their status as women and as disabled persons, and hence represent one of the most marginalised groups in society.

• Disabled girls attend school less frequently than disabled boys[x].

• Disabled females are twice to three times more likely to suffer physical and sexual abuse than non-disabled females[xi].

Goal 4: Reduce child mortality

• Mortality of disabled children can be as high as 80% even in countries where overall under-five mortality is below 20%[xii].

• 1 in 10 children are born with, or acquire, an impairment[xiii].

• For every child killed by armed conflict, three are injured or permanently disabled. Over 10 million children are psychologically traumatised by armed conflict[xiv].

Goal 5: Improve maternal health

• As many as 20 million women a year suffer impairments and long term complications as a result of pregnancy and childbirth, hence approximately every minute, 30 women are injured or impaired through childbirth[xv].

• A major cause of impairment in children includes abnormal pre-natal or peri-natal events[xvi]. A large number of perinatal impairments in children can be prevented or ameliorated by skilled birth attendants.

Goal 6: Combat HIV/AIDS, malaria and other diseases

• HIV/AIDS, Malaria and Tuberculosis are the 1st, 6th and 9th leading causes of losses in disability-adjusted life years (DALYs) in high mortality countries respectively[xvii].
DALYs are the number of healthy years of life lost due to premature death and disability.

• The estimated annual global burden of malaria is 1.1 million deaths, 300-500 million cases, and 44 million DALYs[xviii]. About 1 in 10 children suffer neurological impairment after cerebral malaria, including epilepsy, learning disabilities and loss of coordination[xix].

• Each year, 1% of the global population is infected with Tuberculosis, and 5-10% of those infected become sick or infectious, and can develop disabilities (e.g. epilepsy). The global burden of disease is over 36 million DALYs. The combination of Tuberculosis and HIV accelerates progress of the other disease[xx].

• Globally, about 450 million people have some form of mental or neurological disorder. Major depression is a leading cause of disability, and five of the 13 leading causes of years lived with a disability are mental disorders. Poverty is a powerful determinant of mental disorders, and without support they, and their families, are likely to fall into the vicious circle of poverty and mental disorder[xxi].

Goal 7: Ensure environmental sustainability

Indicator: Proportion of population with access to improved water and sanitation

• Trachoma is a main cause of preventable blindness, with four million people infected worldwide, and six million permanently blinded. Trachoma can be prevented with access to safe water for washing of face and hands[xxii].

Goal 8: Develop a global partnership for development

• The active cooperation and participation of all members in the community is important for achieving sustainable development. National and international organisations in the world community, including Disabled Person's Organisations (DPOs), have an important role to play in the awareness-raising of disability issues, and the empowerment of disabled people and their allies to participate in development. The strengthening of national DPOs and their alliances with relevant organisations in their own country, and in donor countries, should promote good governance with more accountable governments in relation to disabilities in developing countries.

• The inclusion of disabled people into mainstream services is important, along with specialised interventions where necessary, and would constitute a twin track approach to disability in all development activities.

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